

# BREAKING GROUND



## RESPIRE: *The Gift of Time*

[ 3 ]



CONNECTING HISPANIC FAMILIES  
WITH SERVICES [ 5 ]



OPENING DOORS  
FOR INDIVIDUALS WHO  
ARE DEAF-BLIND [ 8 ]



TENNESSEE SPOTLIGHT:  
EAGLE SCOUT NICK HEYDEN [ 19 ]

TENNESSEE  
COUNCIL



DEVELOPMENTAL  
DISABILITIES

## CONTENTS

- 3 Respite: The Gift of Time
- 4 Applications Now Being Accepted for the 2007–08 Partners in Policymaking™ Leadership Institute
- 5 Connecting Hispanic Families with Services
- 6 Braille Transcription Services: Breaking the Code
- 7 Tennessee Braille Resources
- 8 Opening Doors for Individuals Who Are Deaf-Blind
- 9 In Memory of William King
- 10 Visiblility Resolution Passes in Knoxville
- 10 Council Member Breaks Ground in Jackson
- 12 Being Prepared for Emergencies
- 14 Developmental Disability Task Force Update
- 15 News from Pathfinder
- 16 Book Reviews: *Do-si-Do with Autism* and *Does My Child Have Autism? A Parents Guide to Early Detection and Intervention in Autism Spectrum Disorders*
- 17 National Disability Resources
- 18 Tennessee Spotlight

Cover photo by by Ned Andrew Solomon; Blake and Leslie Hill.

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# RESPITE: *The Gift of Time*

BY KELLY TIPLER

If you passed Leslie Hill on the street or in the grocery, she probably wouldn't stand out. She's just a typical person—a loving wife and mother. But life, as it often does, has put Ms. Hill in an extraordinary circumstance. Ms. Hill is a fulltime caregiver for her son, Blake, who has a disability. He's on a ventilator and requires continual, around-the-clock care. Ms. Hill is the one who has taken on the majority of the responsibility for that care, which can be overwhelming at times.

"Sometimes I have trouble doing the little things that everybody takes for granted," said Ms. Hill. "There are times that I can't get out to go to the grocery store or the pharmacy. If a nurse happens to call off because the schedule is not good, I spend days on end in the house. These are the realities on our side. There are a lot of families like ours that are never heard from. It's not a glory job. It's not a glory situation. After a while people kind of forget. But I'm a real live human being—nobody special. I'm not a super-parent, I just happened to be put in a very challenging situation. We need help."



Blake and Leslie Hill.

Fortunately for Ms. Hill and her family, Tennessee has one of the most active and organized Respite Coalitions in the country. The Tennessee Respite Coalition (TRC) advocates for and provides services for family caregivers across the lifespan. Respite is absolutely necessary for caregiving families. It provides an opportunity for families to have healthy relationships under extremely stressful circumstances.

## A Respite Primer

Respite is a necessity for family caregivers, not a luxury. It is essential for keeping families together and ensures that people with disabilities receive the best, most loving care possible.

## What is respite?

Respite is temporary relief for caregivers and families. It is a service in which care is provided to individuals with disabilities and other special needs, while their family caregiver gets some much needed time away.

## Who are caregivers?

Those of us who care for our spouses, parents, children, siblings or other loved ones who face a wide array of special needs, including medical conditions, mental illness and other diagnoses.



The Hill family. Kendall (rear); left to right, Blake, Leslie, and Megan.

## What is the purpose?

Respite is essential for maintaining a quality of life for families and is often referred to as "the gift of time". Respite gives families and caregivers relief from the extraordinary and intensive demands of providing ongoing care. It strengthens a caregiver's ability to continue to provide care in the home, and supports family stability, well-being, and crisis prevention.

## The Tennessee Respite Coalition

The TRC began as a grassroots volunteer advocacy group for family caregivers who rarely received relief from their responsibilities of caring for loved ones. The group, which included the Council on Developmental Disabilities, came together in the early 1990s and mainly was comprised of professionals who were interested in gaining respite for families that had children with disabilities. Based on many other state models, the TRC was built with assistance from an award to the Tennessee Department of Mental Health and Developmental Disabilities through the CISS/Community Organizational Grant.

Over the course of the grant, the founding membership of the TRC grew to more than 1000 members within seven regional groups. The regional community groups met monthly to discuss availability and gaps in Respite services. They networked with one another, advocated, and recognized family caregivers.

At the completion of the Community Organization Grant, the membership decided to continue their efforts and work toward expanding services. In November, 2003, the TRC became a freestanding 501(c)3 non-profit organization, with over 1000 partnering members across the State.

Today, the TRC continues the regional advocacy groups, has over 1400 members, and encompasses several respite programs. The volunteer regional advocacy groups are powerful and supportive in all of the TRC efforts. The regional groups assist in program development, maintenance, and are hoping to assist in promoting fundraising and development.

CONTINUED ON PAGE 4



Kendall (rear), Blake (left) and Leslie Hill. Photo credit: Ned Andrew Solomon.

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The regional groups are made up of "members." The only criterion for becoming a member is to be interested and invested in respite services. There is no cost to become a member. Members are apprised of respite activities in their region and national respite news, and have the opportunity to be an active member in regional meetings, advocate for respite legislation, and participate in events held by the TRC. The members are the backbone of the TRC, and are crucial in carrying out the organization's mission. To become a member, please call 1-888-579-3754, or visit [www.tnrespite.org](http://www.tnrespite.org).

#### Lifespan Respite

The Tennessee Respite Coalition is working hard to unify all respite programs, caregivers and professionals dealing with families that

have loved ones with disabilities and other special needs. Ultimately, the TRC would like to see a statewide Lifespan Respite Program. Lifespan Respite is a coordinated system of accessible, community-based respite care services for caregivers and individuals regardless of age, race, ethnicity, special need or situation.

Respite care is planned or emergency short-term relief to caregivers from the demands of ongoing care for an individual with special needs, or at risk of abuse or neglect. Special needs may include any disability, any chronic or terminal physical, emotional, cognitive or mental health condition requiring ongoing care and supervision, including Alzheimer's disease and related disorders, developmental disabilities, children with special medical needs, and any other condition determined by the State. Crisis respite may also be used to provide a temporary safe haven for the care recipient in the event of an emergency brought on by domestic violence, substance abuse, or a housing, health or job crisis. Basically, this system would wrap its arms around all caregiving families and attempt to meet their needs so that they can maintain the family and caregiving structure.

The TRC and its members have been very active in assisting with the passage of the federal Lifespan Respite act of 2005. This is an authorizing bill, opening an opportunity for congressional appropriations in the coming session. Once appropriated, states will have an opportunity to submit competitive grants to obtain funding for a Lifespan Respite Program. The TRC members—primarily front line caregivers and the professionals who support them—have put Tennessee in a prime position to gain this sort of funding.

*Kelly Tipler is executive director of the Tennessee Respite Coalition.*

## APPLICATIONS ARE NOW BEING ACCEPTED FOR THE 2007-08 PARTNERS IN POLICYMAKING™ LEADERSHIP INSTITUTE.



**Partners in Policymaking is a training initiative of the Tennessee Council on Developmental Disabilities. The Institute is designed to provide adults with disabilities and family members of individuals with disabilities with the latest information on disability policy issues, and to help them become advocates for themselves, and for others in their communities.**

The ultimate goal is to create a productive partnership between people with disabilities and the people who make the policies that affect their lives, and the lives of their loved ones.

Curriculum includes state and federal laws, assistive technology, community inclusion, personal futures planning, employment, history of disability, supported living and family supports. With every new class, an effort is made to incorporate topics that are currently relevant to our class members. Sessions are conducted by local and national experts in the disability field.

► **All applications must be postmarked by April 2, 2007.**



(L to R) Current Partner Tina Marascia, Partner grad Richard Moore, Council Executive Director Wanda Willis, Partner grad Steven Sheegog.

**For an application, or more information about the program, please contact:**

Ned Andrew Solomon  
Director, Partners in Policymaking  
Council on Developmental Disabilities  
Parkway Towers, Suite 130  
404 James Robertson Parkway  
Nashville, TN 37243-0228  
615-532-6556  
[ned.solomon@state.tn.us](mailto:ned.solomon@state.tn.us)

# CONNECTING HISPANIC FAMILIES WITH SERVICES

BY JAN ROSEMERGY

**NAVIGATING SERVICE SYSTEMS TENDS TO BE COMPLICATED**, so imagine how tough it can be for Spanish-speaking families who have a child or adult family member with a disability. Connecting Hispanic families with disability services—as well as with health, education, and social services—is a priority of Tennessee Disability Pathfinder, a project of the Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy University Center for Excellence on Developmental Disabilities (UCEDD).

Leadership for identifying Hispanic disability services statewide is provided by Pathfinder's Hispanic outreach coordinator, Claudia Avila-Lopez. Free information and referral is provided through Pathfinder's Español phones, 615-400-4422 (Nashville), and 615-322-7830 (statewide).

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**"Collaboration is essential for helping families get the services they need."**

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"Pathfinder's Hispanic outreach is distinct from other information and referral services, like 211, because we specialize in disability resources and work directly with families to understand the variety of services needed," explains Ms. Avila-Lopez. "Then we support the family throughout the process and follow up to see that services are obtained."

A Web-linked directory of Español national, state, and community resources is found on Pathfinder's Web site, [www.familypathfinder.org](http://www.familypathfinder.org), which also includes a database of over 1,200 Tennessee agencies searchable by county and service category.

Carolina Meyerson, Pathfinder Hispanic outreach specialist, works one-to-one with Hispanic families at the Woodbine Community Center. She leads Pathfinder's newest Hispanic service, a monthly evening support group for parents of children with disabilities, held at the Vanderbilt Kennedy Family Outreach Center.

"We're especially pleased that we have dads taking part, as well," says Ms. Meyerson.

"Collaboration is essential for helping families get the services they need," emphasizes Carole Moore-Slater, Pathfinder director.

Collaboration was the hallmark of Pathfinder's second annual Hispanic Disability Conference held December 6, 2006, at the Knowles Senior Center. The first panel, Disability Services in the Hispanic Community, highlighted programs of Metro Social Services, the Mental Health Association of Middle Tennessee, and Pathfinder.

In a unique collaboration, these agencies have developed a Web-based directory of Nashville community organizations. Criteria for inclusion include the agency having a staff member fluent in Spanish,

and disability or social service programs that specifically serve Spanish-speaking families. See [www.caminoseguro.org](http://www.caminoseguro.org). The database will be expanded to become statewide.

"We're stronger if we collaborate," stressed Luz Belleza of Metro Social Services. She also emphasized the importance of educating families. "We can coordinate but in the end they need to take the necessary steps."

The Mental Health Association's Luisa Hough coordinates Encuentro Latino, a monthly meeting of agency staff who share information about services and problem-solve together. Interested service providers are welcome. "We work together so well we know one another by first names," Ms. Hough said. "We're friends in action."



(L to R) Claudia Avila-Lopez and Carolina Meyerson, Vanderbilt Kennedy Center Hispanic Disability Outreach, Luisa Hough, Mental Health Association of Middle Tennessee, and Luz Belleza, Metro Social Services. Photo credit: Ashley Coulter

The second panel addressed Health Care Services for Individuals with Disabilities, with presentations by coordinators of Hispanic services at Bridges to Care, TennCare, and Children's Special Services.

The final panel was an overview of services across the life-span, highlighting prenatal services provided by the Vanderbilt Center for Health Services' Maternal Infant Health Outreach Worker program at the Woodbine Community Center, Outlook Nashville's preschool home visiting and center-based programs, and Metro Public School's early childhood and school-age services.

An Hispanic disability conference will be held April 5, 2007, in Memphis in conjunction with the Boling Center UCEDD. For information contact [claudia.avila@vanderbilt.edu](mailto:claudia.avila@vanderbilt.edu), 615-322-7830. Pathfinder also urges persons across Tennessee to inform them of disability and other services focused on serving Hispanic families, as well as Hispanic business or other advocacy networks.

# BRAILLE TRANSCRIPTION SERVICES: BREAKING THE CODE

BY MELISSA FORTSON AND JENNIFER LEGG

FILE PHOTO

Braille is a vital source of information and communication for persons who are blind or whose eyesight is not sufficient for reading printed material. Braille is not a language but a means by which languages such as English or Spanish may be read; persons who are blind or have low vision use their fingers to read this code comprised of raised dots. Braille provides important equal access to information. According to the Braille Plus, Inc. Web site ([www.brailleplus.net/school](http://www.brailleplus.net/school)), "Braille readers can get the information they need, reduce their reliance on others, protect their privacy and participate more fully in their careers and daily life." Print or electronic documents can easily be translated into Braille through the use of transcription services.

A Braille transcriber converts printed text into Braille. Transcription may be done manually or with the use of translation software. It is important to note that the availability of such software allows sighted persons who are not fluent in Braille to transcribe; however, fluency in Braille enables transcribers to format and proofread more effectively. After transcribing a document's contents, the transcriber then prints it using a Braille printer. Braille printers work much like regular computer printers, but emboss the Braille onto heavyweight paper as opposed to printing characters in ink.

## BRAILLE TRANSCRIPTION: THE WHY

Medical advances have resulted in an increased incidence of blindness. "Premature babies are being saved but can be faced with lifelong disabilities. Older adults are living longer and can develop degenerative eye diseases," reports the Web site of the American Printing House for the Blind, Inc. ([www.aph.org](http://www.aph.org)). As the occurrence of blindness increases, the need and importance for Braille transcription increases too. While assistive technology, such as magnifiers and computer software which enlarges or simulates a voice reading print, is increasingly available, there is still a need for Braille. Braille is an alternate format that empowers persons who are blind to be independently literate and is easily substituted for print; many persons who are blind prefer Braille when it is available.

"Technology is great, but expensive," says Carol Francisco of the Middle Tennessee Council of the Blind. Synthesized speech can also be difficult to understand. Ms. Francisco says, "I have always found it difficult to use recipes on tape."

In some cases, the provision of Braille documents allows organizations to comply with applicable laws. Martha Lafferty, senior attorney at the Disability Law & Advocacy Center of Tennessee, says that while there is no legal requirement that specifically requires Braille documents, "the ADA [Americans with Disabilities Act] and similar laws typically require that government entities and private businesses provide effective communication to people with disabilities. If Braille documents are necessary for effective communication,

then government and businesses will typically have to provide them unless doing so would be an undue burden or alteration in services."

Brenda Dillon, a member of the Tennessee Council of the Blind and Nashville's Mayor's Advisory Committee for People With Disabilities, shares that even when the ADA does not require them to do so, many government offices and private businesses provide Braille forms and applications upon request. "The practice is becoming more prevalent," she says.

**"...having an actual hard copy in my hand, as the speakers talked was more helpful than even I realized it would or could be."**

By providing materials in Braille, organizations not only comply with any applicable laws, but also promote the full involvement and independence of persons who are blind. Ms. Francisco explains: "It is well known that those of us who use Braille are more likely to be employed and hold better paying jobs. After all, it is hard to learn proper spelling and punctuation, if all your reading is done orally."

Ms. Dillon agrees: "When you are not able to read for yourself and are relying on listening, your writing suffers....having Braille enables you to communicate professionally."

Persons with visual disabilities should have equal access to information and resources; agencies demonstrate their commitment to meeting their consumers' needs by providing documents in Braille. Jan Rosemergy, director of communications and dissemination at The Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities (UCEDD), notes that communication and dissemination of knowledge has been a part of the Center's mission since its founding. "We have a responsibility to [communicate] in a way that is accessible for specific purposes and audiences. Accessibility can take many forms. For persons who are blind, we provide our most important print items in Braille."

Braille copies are provided on request and all Center publications are listed on its Web site, which the Center strives to make as accessible as possible for text-reading software; for more information, contact (615) 322-8240 or email [kc@vanderbilt.edu](mailto:kc@vanderbilt.edu).

As a member of the Vanderbilt Kennedy Center's Community Advisory Council, Ms. Dillon appreciates the availability of Braille minutes and agendas. There is a huge communication barrier, Ms. Dillon says, when people refer to printed materials. "It is also hard to discuss and make decisions based on material that is read...when information isn't accessible to you that is accessible to others, it makes you feel inadequate to give an educated or informed response."

**"Having the Braille...helped me to focus...  
and not lose concentration or attention."**

In addition to meeting consumers' needs, providing Braille materials is also good business: "My husband is also blind," says Ms. Francisco, "so we go to restaurants that have Braille menus whenever possible."

#### **BRAILLE TRANSCRIPTION: THE WHERE**

Though there is a nationwide need for increased awareness and availability of transcription services, these services are available in Tennessee. Organizations serving people who are blind should have all pertinent documents and information transcribed into Braille. When they update their written documents and flyers, they should also update their Braille material.

*Insert quotes from Sheri Grigsby, current Partners in Policymaking participant.*

*Melissa Fortson is an information & referral specialist/program coordinator with Tennessee Disability Pathfinder, a joint project of the Council on Developmental Disabilities and the Vanderbilt Kennedy Center UCEDD. Jennifer Legg is an undergraduate social work student at Belmont University who recently completed an internship with the Pathfinder program.*

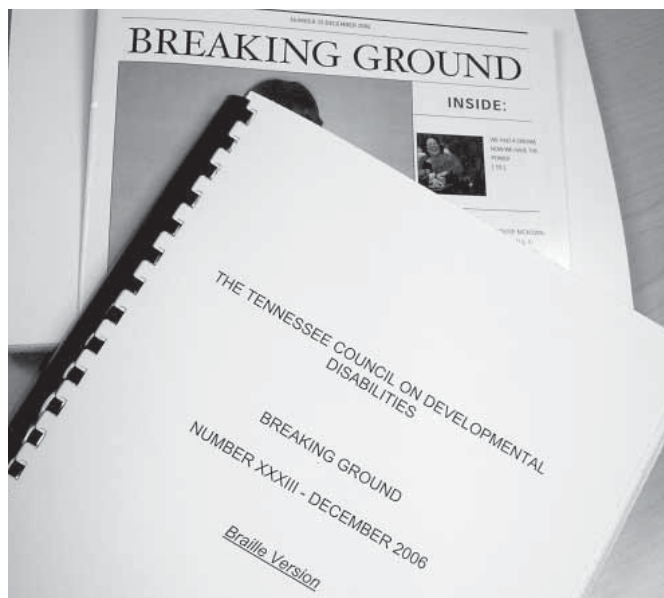


PHOTO: ASHLEY COULTER

## **TENNESSEE-BASED BRAILLE RESOURCES**

The following individuals and organizations provide Braille transcription; for more information on their services, contact the provider directly. Braille materials are also available to students enrolled in Tennessee schools and colleges. For information about or access to Braille services, students may contact their special education teacher, teacher of students with visual impairments, or campus disability student services office.

Katherine Moore, disABILITY Resource Center (Knoxville)  
Email: kmoore@drctn.org  
Phone: 865-637-3666  
Rates: Available upon request

Lois Symington, East Tennessee Technology Access Center (Knoxville)  
Email: lsymington@aol.com  
Phone: 865-219-0130  
Rates: \$1.25 per Braille page

Crumley House Brain Injury Rehabilitation Center (Limestone)  
Email: CrumleyHouse@yahoo.com  
Phone: 423-257-3644  
Rates: Available upon request

Diana Dluhos, Clovernook Printing House (Memphis)  
Email: wclay@clovernook.org  
Phone: 901-523-9590  
Rates: 5 cents/page; \$16/hr; \$7 for binder

Tom Hopton, Center for Independent Living of Middle Tennessee (Nashville)  
Email: Tom\_h@tndisability.org  
Phone: 615-292-5803  
Rates: Available upon request

Charles Couey (Nashville)  
Email: brocharles@bellsouth.net  
Phone: (615) 331-6098  
Rates: Determined on a sliding scale/individual basis

Bill Schenk, Tennessee School for the Blind (Nashville)  
Email: bschenk@tsb.k12tn.net  
Phone: 615-231-7321  
Rates: 10–15 cents/page

# OPENING DOORS FOR INDIVIDUALS WHO ARE DEAF-BLIND

BY CATHY STEGER

"No where to go." "No way to get there." "If I do go, I won't be able to see who is there, or who is talking to me and I won't understand what they are saying." I hear these comments on a daily basis from individuals who are both deaf and blind, and from those who are "nearly deaf-blind"; most individuals who are deaf-blind have some vision and many have some hearing.

Deaf-blind individuals are isolated in a crowded room. Think about it. What would it be like if all you could hear was noise and mumbling? Or if you couldn't see to whom you are speaking, much less be able to hold a conversation? Think how frustrating it would be for people to just move away from you rather than try to carry on a conversation. This even happens with family members. How would it be if you were totally deaf and blind and used sign language as your means of communication, but few of your family or friends use sign language? Add to this your inability to drive and to get around in unfamiliar surroundings.

Enter SSPs, or Support Service Providers. Individuals who are deaf-blind can and should be able to enjoy the same activities that everyone else enjoys. SSPs can help make this possible by serving as the eyes and ears for the person who is deaf-blind. They create access to the community by providing transportation, by being sighted guides, and by facilitating communication through whatever means is preferred by the individual who is deaf-blind. These services allow the individual who is deaf-blind to gain, regain, or maintain optimal independence, at work, for activities of daily living and responsibilities, and during leisure time!

But SSPs are not miracle workers. They are not interpreters. They are not "personal assistants" who provide personal care or make decisions for the individual who is deaf-blind.

SSPs come from all walks of life. They may be family members or friends, interpreters, interpreting students, sign language students, and may be hearing, hard of hearing, or deaf.



Harold Hayes (Right) and friend talk at camp.

Currently, in most areas of the country, SSPs are volunteers. In Tennessee, the deaf-blind organizations are trying to get a referral pool of SSPs, whom we will train, and one day we hope we will have a method to pay for some services. Knoxville currently has a voucher program which is funded by an annual golf tournament. Each individual who is deaf-blind is given six vouchers a month, worth \$10.00 each, to "hire" deaf SSPs. The selected deaf SSPs have provided volunteer services to the deaf-blind community for many years. At the end of the month, they are able to redeem their vouchers for a check.

**Deaf-blind individuals are isolated in a crowded room. Think about it. What would it be like if all you could hear was noise and mumbling?**

Funding for SSPs has become a national effort. This past summer, representatives of AADB (American Association of the

Deaf-Blind) requested funding for three pilot projects, one in Seattle, one in Texas, and one in Maryland. These are states which already have active SSP programs but need to be studied further in order to get the information to justify a National Program through which SSPs would be trained, certified and paid, much as Interpreters are at this time. It is an effort to guarantee the availability of quality SSP services for every individual who is deaf-blind.

For further information on SSPs, look on the AADB Web site: [www.aadb.org](http://www.aadb.org), SSP White Paper.

*At the time this article was written, Cathy Steger was deaf-blind coordinator with the Division of Rehabilitation Services, Tennessee Department of Human Services.*



## *In* MEMORY of *the* INESTIMABLE WILLIAM KING

BY JOYCE ELAINE SIEVERS

AS A FAMILY SUPPORT COORDINATOR AT PACESETTERS, INC. IN COOKEVILLE, I MET WILLIAM KING IN THE FIRST MONTH OF THE INCEPTION OF THE FAMILY SUPPORT PROGRAM IN JULY, 1993.

William's first contact with our agency was by phone with Gaile Palmer in our business office. William didn't hesitate to express his anger and frustration with the "run-around" he had experienced due to the "red tape" in programs, being turned down or being sent to one source after another, and not finding help anywhere. William had definitely soured on accessing any help from the "government". Gaile gave me William's number, and a few days later I visited William in his home to determine his eligibility for Family Support.

Due to progressive paralysis from the waist down, diabetes and heart problems, all functional aspects of William's life were affected except language. He could not stand, walk or crawl, and relied on a manual wheelchair for his mobility. William's request from Family Support was \$385, for hand-controls for his '73 Chrysler Newport. With hand controls, he could maintain independence while doing errands for himself.

In August, William's request for hand controls was approved. In October, a friend took William to Nashville for the installation, and he was able to drive locally again.

In the ensuing years, we kept in touch. The following is a letter from William dated July 18, 1995.

**Thank you for the phone number of the Tenn-Care Advocacy program in Nashville. Your knowledgeable assistance enabled me to complete my application and obtain Tenn-Care insurance. Once again you have expedited my wanderings through the bureaucratic labyrinth. I shall be eternally grateful.**

**Sincerely,  
Your Humble, Obedient Savant, William King**

Over the years, I discovered that William had a great sense of humor and a way with words. He made his thoughts known with a subtle twist of a verbal knife, and a very caring heart.



Joyce Sievers (left) with William King. Photo credit: O.J. Cummings.

When William was no longer able to drive or operate his wheelchair due to his progressive paralysis, he donated his hand controls to a young paraplegic and his wheelchair to a young man with Multiple Sclerosis. Despite William's limited income of \$661 per month, he sent \$50 each month to the Family Support program to be used for someone in need. Until William passed away in 2003, countless families were helped with William's monthly \$50. And, while William never told me, another of our families indicated that he had also helped them financially from time to time.

I share this story about William King in memory of a dear friend, and because his story tells you about the difference the Family Support program can make, simply because of its flexibility. William made only one financial request from the program during 10 years: \$385 for hand-controls for his car. Any other requests were for information.

In response to that support, William donated his hand-controls and wheelchair to someone else when he could no longer use them, and donated his limited finances and warm heart to others who were in need, with no strings attached. The giving goes on.

What an incredible program and what incredible individuals we, as coordinators of the program, are so often given the gift of meeting.

*Joyce Elaine Sievers is Chair of the Council on Developmental Disabilities and Family Support coordinator at Pacesetters, Inc. in Cookeville.*

# VISITABILITY RESOLUTION PASSES IN KNOXVILLE

BY STEPHANIE B. COOK

On December 19, 2006, Knoxville's City Council overwhelmingly supported a resolution that asks the Metropolitan Planning Commission (MPC) to consider modifications to the zoning code to better assure availability of housing designed to meet the needs of persons with disabilities. While the resolution was put forth by Councilman Rob Frost, all other eight City Council members signed on as co-sponsors before passage.

Visitability is a concept that creates accessible private housing. Minimum features include:

- one "zero step" entrance on an accessible path of travel from the street, sidewalk, or driveway that has no step or threshold to block a wheelchair or trip a person with limited mobility;
- doorways that provide 32 inches of clear space throughout the home's main floor and hallways that provide 36 inches of clear width;
- basic access to a half or preferably a full bath on the main floor with sufficient length and width for a person using a wheelchair to enter and close the door.

At this meeting, six individuals with and without disabilities spoke in favor of the resolution, and, more importantly, for the concept of Visitability in general. It was evident that the Council was impressed by the passion and commitment shown by all who spoke.

Within the meat of the resolution, it is suggested that one in ten new homes be built to the VISIBLE standard. "To me, it is of paramount importance that as a result of this process we have a portion of new homes constructed that can accommodate an important, and growing, part of our society," said Councilman Frost. Personally, I think that all new homes should be built to this standard, with the exception of absolute impracticality. But I'm not worried, for I know that once the study is done and it is made evident how very little cost Visitability adds, it will be easy to see the merit in making all new housing visitable.

For now, the City's legislative body is the only one to act on increasing accessible private housing, but I also am confident that once the study is finalized and recommendations are made, the County will be an interested and willing partner in this endeavor.

Municipal legislation that includes Visitability is not new. Atlanta, Georgia, was the first, thanks to the tireless efforts of Eleanor Smith and Concrete Change. Since then, Austin, Texas, and Pima County, Arizona, have adopted similar ordinances. Even more promising, the U.S. Conference of Mayors passed a Visitability Resolution in 2005, encouraging local and state initiatives to promote visitable housing.

I believe that the momentum of support will continue to grow. It is my sincere hope that one day the entire State of Tennessee will have adopted legislation that provides persons with disabilities



Stephanie Cook  
Photo credit: Lynette Swinford.

## A COUNCIL MEMBER BREAKS GROUND IN JACKSON

BY RANDY OLIVER

My struggles with the city of Jackson began in 1975. As a wheelchair-user, it was a major problem finding accessible parking and curb cuts, gaining entry to stores, businesses, public restrooms, movies or public transportation. It was even a problem to access major public buildings, structures like City Hall, the courthouse and the post office. The city was using section 504 and the South Carolina building codes for all of their structures, since this was before the Americans with Disabilities Act (ADA) was put into place.

I had been to the local newspaper, the *Jackson Sun*, several times between 1975 and 1999 about Jackson's accessibility issues. In 2002, I was approached by Cody Allison, a Nashville attorney, and asked if I wanted to be part of a class-action law suit against the cities of Jackson, Dyersburg and Bartlett. He asked me to do research to find out what Jackson's transition plan was—to become more accessible—and if they even had one.

I contacted Jackson's building inspector, and was told that, to his knowledge, there wasn't a plan for Jackson. The next day I reported that finding to Mr. Allison. The following morning, while working in a local warehouse retail store, I was paged to the front. There to greet me was Jackson's building inspector, with a letter and his card. The letter stated that Jackson didn't have a plan in place, but would be working toward one in the next year.

After mailing the letter and business card to Mr. Allison, I was contacted about a meeting that was set up with Jackson's mayor, the city attorney, the ADA coordinator, the city's contractor and the building inspector.

We met for the first time in the Federal Building to discuss what needed to be in the transition plan. The committee wanted me to go around the city photographing problem areas, and then report my findings, and any suggestions I might have for the best ways to resolve the issues. The city officials agreed to contact Jackson Transit Authority to discuss problems with inaccessible bus stops, and the fact that most of the buses were not equipped with wheelchair lifts.

with the expectation that private housing is accessible, at least to a minimal degree.

Not only is our population aging and living longer—often with a decrease in mobility—but those of us with disabilities now, regardless of age, know how desperately lacking accessible housing is, and how discouraging the search for it can be. Implementation of Visitability can and will change that. Unfortunately, it may not happen quickly, and it definitely won't be easy in some cases. Still, I hope you will join me in appreciating the need for accessible housing options, and seek to change legislation in your own area and ultimately, at the State level.

In Knoxville, Laura Johnson first introduced the idea of including Visitability in new private housing. Ms. Johnson was seeking a new home for herself and learned that she had no readily accessible options, and that all the homes she considered would require a retrofit. As a result, she began to push the concept of Visitability, and garnered support for it in numerous circles, including persons with disabilities and seniors, and local organizations with an interest in disability or senior issues. Currently, Ms. Johnson is in the process of building her very own accessible home, and using it as a model for all those willing to listen and learn.

Now the City Council has encouraged the MPC to study what Visitability can do for housing in general, with the hope that accessible housing for all is just over the horizon.

And they say one person can't make a difference!

*Stephanie B. Cook represents the East Tennessee Development District on the Council and is disability services coordinator for the City of Knoxville.*



Randy Oliver

Photo credit: Christy Wells-Reece

Our second committee meeting was held in the new City Hall. We discussed the problems I had uncovered, and my recommendations for how they could be resolved easily.

Mr. Allison asked the city to put together a timeline for Jackson to begin correcting the accessibility barriers.

At a third meeting, we discussed potential changes to the plan to address older buildings that fell under a Grandfather clause, or how they could make the historical part of the city accessible without destroying the

beauty of the original buildings. Mr. Allison and I explained the ADA guidelines, which showed how the historical buildings could remain intact, but become accessible too.

Our last meeting was scheduled to be held in the Jackson City Courthouse. Invitations were sent out to the community, including local businesses, to allow them to ask questions or make comments about the

## TEXT OF THE U.S. CONFERENCE OF MAYORS VISITABILITY RESOLUTION, JUNE, 2005

WHEREAS, the U.S. 2000 Census indicates that approximately 20 percent of the American population has a disability, and that by 2030 there will be over 70 million seniors; and  
WHEREAS, with the population aging and the likelihood of developing a disability or other mobility limitations increasing with age, the growth in the number of people with disabilities can be expected to rise dramatically; and  
WHEREAS, only five percent of new single family homes and town homes built with federal assistance require any access features that make it possible for people with disabilities to live or visit; and  
WHEREAS, visitability is an inclusive design approach that integrates a limited number of crucial accessibility features, such as no step entries, doorways with 32' clear passage space and at least one accessible bathroom into newly built homes; and  
WHEREAS, visitability features would allow seniors to stay in their homes longer and people with disabilities to visit friends and families in their homes, thereby enhancing quality of life and community living; and  
WHEREAS, numerous municipalities and states across the country, including Chicago, Naperville, Bolingbrook and Urbana, Illinois; Atlanta, Georgia; Pima County, Arizona, Vermont, Texas and Kansas have adopted visitability standards in their building codes; and  
WHEREAS, the Inclusive Home Design Act of 2005 would require all newly constructed single family homes and town houses receiving federal funds to meet basic visitability features; and  
NOW, THEREFORE, BE IT RESOLVED that the U.S. Conference of Mayors strongly supports the independence of persons with disabilities and seniors by promoting the concept of including visitability standards to increase access to the homes of friends, family and neighbors; and  
BE IT FURTHER RESOLVED, that the U.S. Conference of Mayors supports local and states initiatives to promote visitable housing.

*According to information obtained by Breaking Ground, representatives from Germantown, Hendersonville, Memphis and Nashville attended the conference in 2005.*

specific details of the transition plan. At that time, the transition plan was put into place, with timelines for making Jackson more accessible.

For me, it had been a 30-year battle, and a sweet victory. For those who come behind me with vision or mobility challenges, it won't be as difficult. Living in or just visiting our city will be a friendlier experience for people with all kinds of disabilities. In the end, isn't that what we all want? Just to be as independent as we can be, as we go through our daily lives. So remember: never give up the fight. We can do it if we stick together!

*Randy Oliver represents the Southwest Development District on the Council on Developmental Disabilities.*



# BEING PREPARED **FOR** EMERGENCIES

BY JAN ROSEMERGY

**Government is responsible—but so are you.** This is the “take-home” message for individuals and families, for service providers and agencies, as each community and county in Tennessee and in every state plan for emergencies. In the wake of Hurricane Katrina, everyone is concerned—but no one more so than individuals with disabilities, who may be especially vulnerable in an emergency and whose unique needs are too often overlooked or not well understood by government emergency planners and responders.

The good news is that a great deal is happening at the federal, state, and local levels. Tennessee is striving to be a leader in emergency preparedness for individuals with “functional needs.” Emergency planning is a priority of State agencies and of the Tennessee Developmental Disabilities Network.

## NATIONAL ACTION

National action was spurred by the aftermath of Hurricane Katrina. Pat Morrissey, commissioner of the Administration on Developmental Disabilities, U.S. Health and Human Services, personally visited sites in Louisiana and Mississippi in September, 2005. She saw first-hand the deplorable conditions of individuals with disabilities in emergency shelters, as well as the struggle of disability service providers to provide care. She returned to Washington, determined to mobilize for improved emergency planning for individuals with disabilities.

Commissioner Morrissey gained the collaboration of leaders of other federal agencies. In June, 2006, a national three-day “Working Conference on Emergency Management: Individuals and Disabilities and the Elderly” was held in Washington, D.C. Each governor appointed a delegation of their key state officials responsible for emergency planning.

Governor Bredesen appointed Kendyl Stokes, Tennessee Emergency Management Agency (TEMA); Judy Eads, Tennessee Department of Health; Anna Smith, Office of Homeland Security; Kathy Zamata, Tennessee Council on Aging and Disability; and Juli Gallup, Disability Law and Advocacy Center of Tennessee. Terri Urbano, Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (UCEDD), also attended as a recorder.

National leaders updated state delegations about emergency planning for people with disabilities, including the need to include individuals with disabilities as participants in the planning process. Delegations also worked together on preparation and recovery issues.

Ms. Eads, then the Tennessee assistant commissioner of health responsible for emergency planning for persons with functional needs, indicated that each state is now providing quarterly progress reports to the National Council on Disability. “Governor Bredesen is very supportive,” Ms. Eads said, “as is TEMA. We have the support of State government to do what we need to do.”

## TENNESSEE ACTION

At the time of the national conference, Tennessee had a draft plan of guidelines and principles for use in caring for individuals with functional needs during disasters or emergencies. Ms. Eads explained that, in an emergency, each State department has a specific assigned role, including a designated staff person who immediately reports to TEMA, the coordinating agency, on a 24/7 basis throughout the emergency. The Department of Health’s role is to address public health and medical services.

Following the national conference, the Tennessee delegation formed an Executive Committee. As an initial step, they recommended a stakeholders meeting, which Ms. Eads, with the support of Dr. Urbano, director of health and training for the Vanderbilt Kennedy UCEDD, helped organize. The “Tennessee Emergency Preparedness Stakeholders Meeting for Individuals with Disabilities and the Elderly” was held in Nashville last November. A broad net was cast to invite individuals with disabilities and family members, service providers, and advocates to participate in this information session.

At the meeting, Ms. Eads reviewed the charge from the June national conference. Cecil Whaley, Jr., TEMA director of planning, training, and exercises, reviewed the current plan. After a group brainstorming session, participants identified next steps. “We had a great turnout,” Ms. Eads said. “People were very interested and engaged and have volunteered for the ongoing work.”

The outcome is that five working committees have been organized: Training and Education, Long-Term Recovery, Planning, Public Awareness, and Resources.

#### MEETING FUNCTIONAL NEEDS

Ms. Eads indicated that the national conference participants discussed preferred terminology, and adopted “functional needs” as the best general descriptor. Populations with functional needs in a mass casualty event include, but may not be limited to, the following: children, persons with physical or cognitive disabilities, persons with pre-existing mental health or substance abuse problems, frail or immuno-compromised adults and children, non-English speakers, persons with dementia or reduced activities of daily living, and homeless and transient populations.

“Our judgment,” Ms. Eads indicated, “is that instead of setting up ‘special needs shelters’ or trying to make shelters accessible in all the ways necessary, a better approach for the first line of response is to relocate individuals with functional needs to vacant beds in licensed health care facilities, other than hospitals. They already have, for example, accessible bathrooms and other accessible facilities, clean/dirty isolated areas, and staff trained to meet functional needs.”

She contrasted this with the situation during Hurricane Katrina, when individuals with functional needs were in large, crowded community shelters, with accessible bathrooms at considerable distances, with lack of trained staff, and lack of privacy.

Once placed in a licensed health care facility, needs would be assessed and plans for subsequent care would be made and implemented. “I think this is a very innovative model,” said Dr. Urbano, who was involved in supporting persons with disabilities through hurricanes during her years of service at the Mailman Center for Child Development UCEDD in Miami, Florida. “We should be proud of Tennessee because it ranks as one of the most prepared states in the U.S. State leaders are very receptive to learning more about the needs of people with disabilities and how they can enhance the current plans to better address their needs.”

#### BE PREPARED

Tennessee has one of the highest risks for disasters among all states. Possible disasters include tornadoes, floods, earthquake, or a nuclear power plant accident. These are all the types of incidents that could affect large numbers of people, with most affecting infrastructure—roads and communication systems—as well.

“People are reluctant to think about bad things happening to them,” Dr. Urbano said. “The truth of the matter is—people have

to assume individual responsibility because in a mass disaster, government does not have enough people to go around. Each individual and each family needs to assume responsibility for learning more and for developing individual and family response plans for a disaster. The need for individual plans is particularly important when considering persons with disabilities.”

Dr. Urbano recommends initial steps such as using planning tools available to the general public through the Red Cross, FEMA, or the American Academy of Pediatrics, which offers guidelines for children with special health care needs. Developing specialized planning tools for individuals with disabilities also is a priority of the Association of University Centers on Disabilities.

A truism of emergency planning is that “All emergencies are local.”

That is to say, the first response is at the local level. One way that individuals with disabilities and family members, service and advocacy organizations can be prepared is to contact the emergency planning agency in their community or county to learn that agency’s plan and how persons with disabilities can have their needs met in the event of an emergency. Plans need to be made for action in both home and work settings.

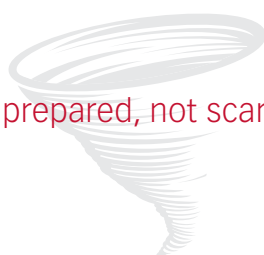
One of the challenges at the local level is knowing where an individual with functional needs is geographically located. A solution underway both nationally and in Tennessee uses Geographic Information System (GIS) technology. GIS enables government agencies and emergency responders at all levels to share data overlaid on detailed maps. For example, GIS can simultaneously map streets and houses, hospitals and licensed health care facilities, health care providers, emergency responders—and eventually the local location of individuals with functional needs. Ms. Eads indicated that Tennessee is moving forward on using GIS technology for emergency planning and response.

“Be prepared, not scared,” Dr. Urbano emphasized. “If you learn what you need to do to prepare for and respond to an emergency, you’ll greatly enhance your chances for survival and recovery. The steps are easy and do-able. Just as we take care of our health or take our medication daily, we need to plan for emergency events. Knowledge is power.”

*Members of the Tennessee Developmental Disabilities Network are the Council on Developmental Disabilities, the Disability Law and Advocacy Center of Tennessee, the Boling Center for Developmental Disabilities at the University of Tennessee—Memphis and the Kennedy Center at Vanderbilt University.*

*Jan Rosemergy is director of dissemination for the Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities.*

“Be prepared, not scared”



## DEVELOPMENTAL DISABILITIES TASK FORCE UPDATE

BY WILLIAM EDINGTON

Although developmental disability is a term that many people mistakenly equate with mental retardation, it actually encompasses many types of disabilities that affect a person's physical or cognitive functioning capacity. Developmental disability may include, but is not limited to, autism, cerebral palsy, cystic fibrosis, spina bifida, and other conditions occurring before age 22 that result in significant deficits in functioning in such daily living activities as eating, dressing, grooming, bathing, toileting, etc.

While appropriate services can assist individuals with developmental disabilities to live productive and fulfilling lives in their own homes and communities, it is unfortunate in Tennessee that comprehensive home and community-based services are available only for persons who have a diagnosis of mental retardation. While Family Support services are available for people who have a developmental disability due to other situations and are widely applauded, those services are not always comprehensive enough to help people with more significant disabilities remain in their own homes and communities. Furthermore, Family Support has a waiting list of over 5,000 people and no opportunities for additional funding appear to be available in the near future. This leaves nursing homes as the only alternative for persons with developmental disabilities who need more support than their families can provide.

In order to address this inequity, the Council on Developmental Disabilities and the other three founding members of the Alliance for Disability Policy (Disability Law & Advocacy Center of Tennessee, The Arc of Tennessee, United Cerebral Palsy of Middle Tennessee) developed legislation in 2006 that was subsequently passed by the Tennessee General Assembly. This legislation called for the Division of Mental Retardation Services (DMRS) to establish a task force to conduct a statewide needs assessment:

- to study the needs of persons with a developmental disability other than mental retardation for whom comprehensive home and community-based services do not exist,
- to identify the capacity of the system to meet such needs, and
- to develop a plan to provide cost-effective home and community-based services for such persons.

As called for in the legislation, DMRS has established a task force with members that include persons with disabilities, family members of persons with disabilities, disability advocates, representatives of State departments serving persons with disabilities, and universities. The Task Force has been meeting since August, 2006, and has developed working committees to address eligibility issues, the needs assessment, capacity and infrastructure issues, and rules and regulations.

Some issues the committees and the Task Force will confront include:

**Eligibility and Funding** Revisions to the State's laws governing mental health and developmental disabilities in 2000 expanded eligibility from mental retardation to developmental disabilities. However, no funding has been allocated to provide services to these persons. Although the State's laws now authorize services to be provided to persons with developmental disabilities, Tennessee's rules governing Medicaid Waiver funding for long-term care services have not been revised to incorporate persons with developmental disabilities other than mental retardation. The federal government permits each state to determine which groups of people with disabilities may enroll in Medicaid Waiver programs. Research conducted by the Alliance on Disability Policy indicates that approximately half the states in the country do use their Medicaid Waivers to serve persons with developmental disabilities, not just persons with mental retardation.

**Services** The Task Force has disseminated a Needs Assessment to approximately 3,600 persons with developmental disabilities and to over 50 disability organizations to solicit feedback on the types of home and community-based services that are needed by persons with developmental disabilities in their Tennessee communities.

**Best Practices** in areas such as self-determination, fiscal intermediaries, support brokerage, and person centered planning.

**Capacity & Infrastructure**, which will address issues such as needed programs, enrollment processes, provider network, etc.

The Task Force shall complete its assessment and plan by June 30, 2007. DMRS is charged with presenting the Task Force's findings to the State House and Senate Government Operations committees no later than January 15, 2008.

*William Edington is public policy coordinator for the Council on Developmental Disabilities.*

### TENNESSEE DISABILITY MEGA CONFERENCE

**When?**

May 31 – June 2, 2007

**Where?**

Nashville Airport Marriott

**Why?**

Workshops and interactive sessions on a variety of disability-related topics presented by local and national speakers

**How?**

For more information including registration forms please visit the conference Web site at:

**[www.tndisabilitymegaconference.org](http://www.tndisabilitymegaconference.org)**

- EVENING ENTERTAINMENT •
- NETWORKING OPPORTUNITIES •
- INFORMATIVE EXHIBITS •

TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES

DISABILITY PATHFINDER

VANDERBILT KENNEDY CENTER FOR RESEARCH ON HUMAN DEVELOPMENT

# NEWS FROM PATHFINDER

BY MELISSA FORTSON

Tennessee Disability Pathfinder has phone, Web, and print resources in English and Spanish to connect the Tennessee disability community with service providers. Referral services, free of cost, are provided to persons with disabilities, family members, service providers, and advocates. Pathfinder is a joint project of the Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy Center for Research on Human Development.

## PATHFINDER OFFICE MOVE

No longer located at 1810 Edgehill Avenue, the Pathfinder office has moved to 1114 17th Avenue South, Nashville TN 37212. We are pleased to share a space with the Vanderbilt Kennedy Center Recreation & Art program. While an open house will be held soon, we welcome you to stop by and visit anytime. Though we have a new address and fax number, our telephone numbers remain the same (see below).

## FOR FURTHER INFORMATION

Tennessee Disability Pathfinder

(615) 322-8529 (Nashville area, English & Español)

(800) 640-4636 (toll-free, English & Español)

(615) 321-8834 (fax)

TTY/TDD users: please dial 711 for free relay service

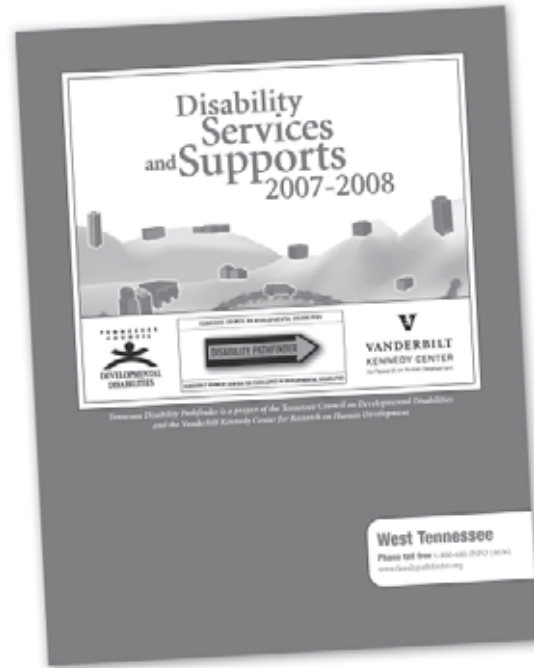
[www.familypathfinder.org](http://www.familypathfinder.org)

[tnpathfinder@vanderbilt.edu](mailto:tnpathfinder@vanderbilt.edu)

We have an auto attendant system that prompts callers to press 1 for Pathfinder, 2 for Pathfinder in Spanish, or 3 for Recreation & Art. When a caller selects 1, the call "rolls" through available Pathfinder staff. When a caller selects 2 or 3, s/he is transferred directly to Claudia (Spanish) or Gretchen (Recreation & Art). Callers can enter an extension anytime:

- 10 Melissa Fortson
- 11 Claudia Avila-Lopez
- 12 Access Nashville (Suzanne Ezell & intern)
- 13 Carole Moore-Slater
- 14 Gretchen Herbert
- 15 Ashley Coulter
- 16 Pathfinder intern (Dawn Callas)

*Melissa Fortson is information & referral specialist/program coordinator with Tennessee Disability Pathfinder.*

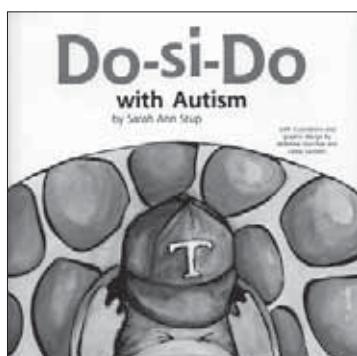


## 2007 DIRECTORY AVAILABLE FOR PRE-ORDER

Pathfinder publishes the *Tennessee Disability Services & Supports Directory*, a statewide directory in three regional volumes (East, West, and Middle Tennessee). The 2007 edition of the directory, which lists statewide and local disability-related resources, is nearing completion. To reserve your copies, please call the Pathfinder office at 800-640-4636 or send your name, e-mail address, and phone number to [tnpathfinder@vanderbilt.edu](mailto:tnpathfinder@vanderbilt.edu); please indicate how many copies you would like of each volume and include "directory pre-order" in the subject line of your message. Upon publication of the directories, we will mail copies to those who have pre-ordered, along with an invoice requesting payment. Directories will cost \$25 each.

In addition to the print directory, Pathfinder continues to offer bilingual telephone information and referral service. Pathfinder Web site users have access to the Tennessee Disability Pathfinder Database, which lists statewide disability resources, and the Pathfinder Disability Calendar, a list of disability-related events across Tennessee.

# BOOK REVIEWS BY LAURA LUM CORBY



Sarah Ann Stup, *Do-si-Do with Autism*. (Victoria, BC, Canada: Trafford Publishing, 2006), 30 pp.

Sarah Ann Stup is a young woman with autism whose writing provides readers an excellent bird's eye view of the many daily difficulties encountered in autism. Though Ms. Stup is

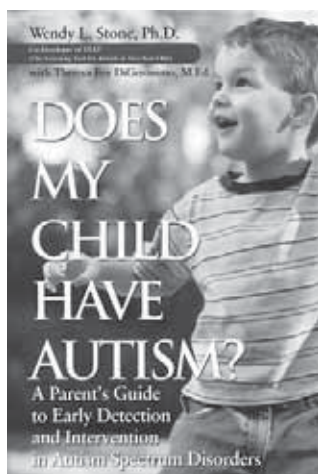
unable to speak physically, she has found her voice in the written word. She encourages readers to empathize with autism by sharing her struggles and explaining her unique and often uncomfortable circumstances.

Ms. Stup gives readers a glimpse of autism through the eyes of one experiencing it, yet is able to reconcile her differences and find common ground with her peers. Walking with Ms. Stup through her school day journey simply emphasizes the complexities of autism and the need for acceptance and understanding.

This is an excellent book for all ages, but especially helpful in introducing young readers to the world of autism in an age-appropriate way.

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Wendy L. Stone, Ph.D., *Does My Child Have Autism? A Parents Guide to Early Detection and Intervention in Autism Spectrum Disorders*. (San Francisco, CA: Jossey-Bass, 2006), 206 pp.



*Does My Child Have Autism?* is a book written for the benefit of parents who might be wrestling with a potential autism diagnosis. Wendy Stone provides an easy to understand overview of autism spectrum disorders and elaborates on those critical early signs that can often be missed by those not specializing in this field. As the founder and director of the Vanderbilt Treatment and Research Institute for Autism Spectrum Disorders (TRIAD), Dr. Stone has used her clinical experience to

provide insightful commentary and information greatly needed in the areas of early identification and appropriate diagnostics, which are crucial to optimal outcomes.

The book appropriately outlines the primary symptoms of autism, the often hidden symptoms of autism, and clarifies the misconceptions often associated with an autism diagnosis. There are also excellent suggestions for dealing with the "Watch-and-Wait Physician," citing the importance of proactively moving towards a proper diagnosis and early intervention services as soon as possible.

"There is no debate or doubt: early intervention is your child's best hope for the future." (p. 100) The early intervention chapter covers many of the most commonly used strategies and therapies, giving examples and the rationale for each. This chapter clearly indicates the necessity for individualization of interventions, as there should be no "general package or predetermined curriculum that is not tailored to the needs of the individual child." (p. 141)

There is some question pertaining to the opinions and recommendations regarding Early Intensive Behavior Intervention (EIBI) and Complementary and Alternative Treatments (CAM). The author states, "Research findings support the use of discrete trial training as a teaching tool; however, initial research findings of dramatic improvements for children participating in EIBI have not been replicated by other scientists to date." (p. 128)

To the contrary, several replication studies recently have been completed, one of which was conducted by the Wisconsin Early Autism Project. To view the preliminary results of one of the studies replicating Lovaas' treatment and findings, visit <http://www.wiautism.com/pdf/ReplicatingLovaas1999.pdf>. Based on scientific research, early, intensive, one-on-one behavior intervention (ABA) is to date still the most effective and critical form of early educational intervention for children with autism.

"Although there are many different types of CAM therapies, they all share one thing in common: a lack of scientific evidence supporting their safety or their effectiveness in treating the symptoms and conditions for which they are used." (p. 130) This type of blanket statement regarding CAM therapies is misleading, and omits important facts crucial to give a balanced picture. Scientific studies take years to complete, and, although many more studies are desperately needed in the area of CAM therapies, there are many families who don't have years to wait.

There are numerous credible studies already in existence documenting the efficacy of many of these therapies. There are also many concrete tests available to check for specific issues such as gastrointestinal problems, metabolic issues, immune system dysfunction, neurotoxicity, chemical imbalances, and much more. The Autism Research Institute Web site hosts a large number of scientific studies to help educate both the families and professionals in the field regarding new and emerging scientific links and information in the field of autism. To view the current research available on these topics, visit <http://www.autismwebsite.com/ari/dan/scientificfoundations.htm>.

The author refers to a "Quick Elimination List" (p. 141) designed to rule out treatments and interventions that boast of quick cures and offer false hope. While every statement made within the quick elimination list is appropriate and accurate, it's also important to point out that parents should never lose sight of hope or completely rule out any intervention simply based on the opinions of others, good, bad, or indifferent. Thorough investigation should take place regarding any proposed plan of treatment or intervention to determine the best course of action for each individual.

*Does My Child Have Autism?* also features a helpful appendix, including the Modified Checklist for Autism in Toddlers (M-CHAT), diagnostic criteria for autistic disorders, and valuable resources for further investigation of autism spectrum disorders. I would recommend this book as a diagnostic assistance tool for parents of a child with suspected autism. I would, however, strongly suggest that the readers pursue additional research into the efficacy of the many therapies that were discredited, in what appears to be a shortsighted and biased review.

Autism is a bio-neurological disorder that presents through maladaptive behaviors and deficient skills. Although addressing the behavioral and educational aspects of this disorder are crucial, it is equally as important to address the many underlying medical and neurological problems that are scientifically emerging as patterns within the spectrum. The jury is still out on many of these interventions, which potentially hold great hope for individuals struggling with autism spectrum disorders. Working with highly skilled physicians, who understand biochemistry, the intricacies and individuality of the disorder, and the safe approaches to intervention, is the key.

*Laura Lum Corby is Founder/CEO of the Autism Solution Center, Inc., in West Tennessee. She is a graduate of the 2002–03 Partners in Policymaking™ Leadership Institute, and the parent of a child with an autism spectrum disorder*

## NATIONAL DISABILITY RESOURCES

BY TRACI FLEISCHMAN

### Livable Communities

The National Council on Disability (NCD) published a report, *Creating Livable Communities*, that identifies six strategies that can be implemented at the federal and local levels in U.S. to make American communities more livable for people with disabilities. The report also offers eight recommendations for the legislative and executive branches of the federal government and states, so that they can proactively adopt strategies and policies that invest in livable community outcomes. This report is the third in a series. The two previous reports include *Livable Communities for Adults with Disabilities* (2004) and *The State of the 21st Century Long-Term Services and Supports: Financing and Systems Reform with Disabilities* (2005). To read *Creating Livable Communities*, visit [www.ncd.gov/newsroom/publications/2006/livable\\_communities.htm](http://www.ncd.gov/newsroom/publications/2006/livable_communities.htm) (AAMR 2006).

### Criminal Justice

The Arc of the United States offers a new *Justice Advocacy Guide* for advocates on assisting victims and suspects/defendants with intellectual disabilities. The Guide contains an overview of the criminal justice system and provides advocates with the knowledge and understanding needed to help people with disabilities and their families know what to do once they are in the justice system. Specifically, the Guide addresses four main topics: (1) responding to victimization; (2) responding to arrests; (3) answers to commonly asked questions; and (4) resources for victims and suspects/defendants. For more information on the Guide, visit [www.thearc.org/AAadvocacyGuide.pdf](http://www.thearc.org/AAadvocacyGuide.pdf)

### Health Sciences

The Center for Disability Issues in the Health Professions (CDIHP) provides a Web site that offers products, courses and services, online

resources, and news and announcements for health professions education, and to improve access for people with disabilities to health, health education and other tools for decreasing health care barriers. Online resource topics include *Health Care*, *Higher Education*, and *Employment Resources*. The Health Care topic incorporates how to choose resources on health care and health plans for people with disabilities. For more information, visit [www.cdihp.org/index.html](http://www.cdihp.org/index.html)

### NIH Genetics Home Reference

A new online portal is available from the National Institutes of Health (NIH). The portal offers parents and physicians consumer-friendly information on over 200 genetic disorders and related genes. The Web site features an illustrated tutorial that explains the basics of genetics and includes a glossary of genetic terms. The Web site is particularly helpful to parents whose newborns have been detected with a genetic condition and are looking for easy-to-read information on specific conditions. For more information, visit <http://ghr.nlm.nih.gov/>

### Spanish Resources

The Parent to Parent of New York State—Family to Family Healthcare Information and Education Center developed a number of fact sheets in Spanish to assist the parents they serve. Fact sheet titles include: *Navigating Doctor's Appointments*, *Searching the Internet for Medical Information*, *Medication Tips*, *Record Keeping Suggestions*, and *Relieving Stress*. They also have developed a 34-page *Care Notebook*, where families can keep a complete record of a child's medical history. For more information, visit [www.hcbs.org/moreinfo.php/nb/doc/1758](http://www.hcbs.org/moreinfo.php/nb/doc/1758)

*Traci Fleischman is responsible for information dissemination at Vanderbilt Kennedy Center for Excellence in Developmental Disabilities. This compilation includes information resources provided through the Association of University Centers on Disabilities and other organizations.*



# TENNESSEE

## Mayor's Advisory Committee for People with Disabilities Awards Ceremony

The Mayor's Advisory Committee for People with Disabilities, celebrating its 25th anniversary, held its annual Awards Ceremony on November 30, 2006. The Ceremony honors individuals, agencies and companies in the Davidson County area who have promoted the inclusion of persons with disabilities in their community. Mayor Bill Purcell and Brenda Dillon kicked off the event with inspiring opening statements, but the MC responsibilities were handed to Mike Keith, the Voice of the Titans, and the 2006 Tennessee Sportscaster of the Year.

The following are this year's Award recipients.

**The Mack West Children's Award** Robert Wells, age 11

**The Trey Pointer Young Citizen Award** Henry Kunkel

**The Jo Andrews Award** Robert S. Sanders, Jr.

### The Volunteer Award

Karin Kalodimos

Jake and Katie Whitely

Nick Heyden (see story on page 19)

### The Professional Award

Brent Lokey, Epilepsy Foundation

Carol Westlake, The Tennessee Disability Coalition

Anthony Fox, TMHCA

**The Health Care Provider Award** Dr. Julia Thompson

**The Family Award** Brendan Kiefer

**The Employer Award** Publix

**Artist/Entertainer** Ginny Owens

**Legislative** Richard Fulton

**Educator** JoAnne Weatherall

**Entertainment Venue/Attraction** Rebecca Nichols

**Media** Sarah Kelley and Randall Read

### Agency/Organization

Vanderbilt Kennedy Center Treatment and Research Institute for  
Autism Spectrum Disorders (TRIAD)

## From the Youth Leadership Forum Graduate Files

**Spencer Jackson** (Class of 2002) graduated from high school this past year (May 2006) with an honors diploma, and a 4.0 GPA. In his last year of high school, Mr. Jackson took advantage of his high school's dual enrollment program with nearby Motlow State Community College, completing 12 college credit hours. Summer classes and two fall classes brought that total to 24. At his current rate, Mr. Jackson anticipates graduating in December 2008 with an Associate's Degree in Accounting.

**Daphne O'Brien** (Class of 2001) is working full-time at Harding Academy, and going to school full-time at Southwest Tennessee College. She ultimately would like to pursue a degree in Occupational Therapy, based on an experience she had two years ago, working with children with learning disabilities in a school in St. Louis, Missouri.

**Beth Hopkins** (Class of 2002) graduated Cum Laude from Middle Tennessee State University in December 2006. She earned a BA degree in Sociology with a minor in Anthropology and a specialization in Spanish. In addition, Ms. Hopkins has been employed as staff at Easter Seals Camp since the Summer of 2005, and is currently serving as an intern at the Tennessee Council on Developmental Disabilities.

**Kristy Millican** (Class of 2001) is majoring in sociology at the University of Memphis. She's a camp counselor for children with disabilities in Memphis, and is involved with a children's program at her church.

## Partners Grad and Daughter on National TV

Partners grad and author, **Leisa Hammett**, and her daughter, artist Grace Goad, appeared on *The View*, January 25th. The taped, hour-long special segment on autism, hosted by Rosie O'Donnell, aired on January 29th, on ABC.

## TVC Awarded Five-Year Grant

Tennessee Voices for Children (TVC), the statewide family support network, was recently awarded a five-year grant from the U.S. Department of Education to establish a new Parental Information and Resource Center (PIRC). The goals of the federal program are to provide parents with information regarding the range of programs, services, and resources available to help their children receive a quality education that allows them to reach their fullest potential to participate in society and to demonstrate improvements in student achievement, parental choice, school accountability, and supplemental educational services.

# SPOTLIGHT

## High School Student Wins Neighborhood Excellence Award

**Kylie Long**, a student at St. Cecilia Academy, is one of five Nashville students to receive the Nashville Neighborhood Excellence Initiative Award presented by the Bank of America. This award, presented at a ceremony held at the Schermerhorn Symphony Center, is given to outstanding students who have made extraordinary contributions by focusing their talents and passions on projects and missions that impact our community in a positive way. Ms. Long has cerebral palsy.

## Nick Heyden: Bringing the Centennial Park Experience To Visitors Without Sight

Nick Heyden, a Boy Scout and senior at Montgomery Bell Academy, recently earned his Eagle Scout by helping persons with disabilities fully experience one of Nashville's most popular sites. Nick was very aware of the projects other Scouts had done, especially in the area of helping the community, and wanted to attempt something unique. "Many of the other projects didn't seem like things that would continue," said Nick. "I wanted to make a resource available that would perpetuate."

Reading the newspaper one day, Nick saw an article about the lack of Braille signage in government buildings. "So I started thinking about the blind community," said Nick, "and wondered, what can I do?"

His thoughts also turned to the activities he enjoyed doing himself. One of those was taking walks outdoors, and one of his favorite strolls was around Centennial Park. "It's very flat, and there aren't a lot of breaks in the walkway," said Nick. "There are ramps too, so it's accessible, and not many steps, which makes it easier universally."

Nick contacted Brenda and Dan Dillon, two individuals who were mentioned in the newspaper article he had read. The Dillons accompanied Nick on a walk through Centennial, so Nick could determine what kinds of things people who were not sighted would be interested in knowing. He made a practice tape from that experience.

"We talked about how benches are good, as a place to hang out and listen to the running water, and as a landmark," said Nick. "I also used trash cans as landmarks, because you can feel them when you're sweeping with a cane."

He also went on the same walk with other people who are not sighted, to check its accuracy and use-ability. He then made numerous copies of the walking tour tape for future visitors. In



Top: Nick Heyden (center right) and fellow scouts. Bottom: Nick Heyden (left) with Dan Dillon at Centennial Park.

addition, Nick went to great lengths, with the help of some of his Scouting peers, to create 100 identical tactile maps of the park. Using Google Earth, he was able to download a decent-sized aerial view picture of the park. "I outlined it with tile sealant," said Nick. "And then for each of the landmarks I used a brad, stuck into a laminated piece of computer paper, and staples along the road."

Lastly, Nick put his tape onto his computer, and made a digital file of his audio tour, ultimately creating 50 CDs and 20 cassette tapes. "It's not a professional product, but it is authentic!" said Nick. "Eventually, I'd like to see a Web site where nature walks could be available for people who are blind to download. And after doing the work I did at Centennial, it's pretty easy to do."



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# READER SURVEY

Please help the Council to evaluate *Breaking Ground* and to develop strategies for improvement

Please tell us your county of residence (If you are not a Tennessee State Resident, please write 'Non-resident')

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Is the newsletter readable (inviting, easy to read) and clearly written and edited?

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

Do you like the way the newsletter looks?

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

In your opinion, what is the **MOST** valuable type of information we publish?

- ☐ Reports on disability conferences
- ☐ Personal success stories
- ☐ Reports on projects and programs
- ☐ Resource information
- ☐ Other \_\_\_\_\_

In your opinion, what is the **LEAST** valuable type of information we publish?

- ☐ Reports on disability conferences
- ☐ Personal success stories
- ☐ Reports on projects and programs
- ☐ Resource information
- ☐ Other \_\_\_\_\_

What does *Breaking Ground* do well?

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*Breaking Ground* promotes self-determination and community participation for individuals with developmental disabilities

- ☐ Strongly Agree
- ☐ Agree
- ☐ Neither Agree nor Disagree
- ☐ Disagree
- ☐ Strongly Disagree

*Breaking Ground* improves the ability of individuals with developmental disabilities and family members to make choices and exert control over the services and supports they use

- ☐ Strongly Agree
- ☐ Agree
- ☐ Neither Agree nor Disagree
- ☐ Disagree
- ☐ Strongly Disagree

*Breaking Ground* improves the ability of individuals with developmental disabilities and family members to participate in community life

- ☐ Strongly Agree
- ☐ Agree
- ☐ Neither Agree nor Disagree
- ☐ Disagree
- ☐ Strongly Disagree

Which category best describes you?

- ☐ Person with a disability or family member of a person with a disability
- ☐ Direct care provider or other disability-related service provider
- ☐ Educator
- ☐ Non-elected government employee
- ☐ Elected government official or representative of elected government official
- ☐ Other

What could *Breaking Ground* do better?

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